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HOUSE BILL NO. 239

Offered January 10, 2024 Prefiled January 4, 2024

A BILL to amend the Code of Virginia by adding in Chapter 2 of Title 32.1 an article numbered 21, consisting of sections numbered 32.1-73.21 and 32.1-73.22, relating to Advisory Council on Sickle Cell Disease; established; report.

Patrons—McQuinn, Askew, Clark, Cole, Coyner, Henson, Hope, Keys-Gamarra, Laufer, LeVere Bolling, Maldonado, Martinez, Mundon King, Shin, Simon, Simonds, Watts and Willett; Senators: Bagby and Stanley

Referred to Committee on Rules

Be it enacted by the General Assembly of Virginia:

1. That the Code of Virginia is amended by adding in Chapter 2 of Title 32.1 an article numbered 21, consisting of sections numbered 32.1-73.21 and 32.1-73.22, as follows:

Article 21.

Advisory Council on Sickle Cell Disease.

§ 32.1-73.21. Advisory Council on Sickle Cell Disease.

A. The Advisory Council on Sickle Cell Disease (the Council) is established as an advisory council in the executive branch of state government. The purpose of the Council is to advise the Commissioner on the efforts to improve awareness of sickle cell disease and sickle cell trait and the needs of individuals with sickle cell disease.

B. The Council shall have a total membership of seven nonlegislative citizen members to be appointed by the Governor, which shall include two representatives of community-based organizations with experience addressing the needs of individuals with sickle cell disease, two health care providers specializing in hematology, and three individuals who have been diagnosed with sickle cell disease or sickle cell trait or are the family member of a person who has been diagnosed with sickle cell disease or sickle cell trait. Members of the Council shall be citizens of the Commonwealth.

C. After the initial staggering of terms, members shall be appointed for a term of four years. All members may be reappointed. Appointments to fill vacancies, other than by expiration of a term, shall be for the unexpired terms. Vacancies shall be filled in the same manner as the original appointments.

D. The Council shall elect a chairman and vice-chairman from among its membership. A majority of the members shall constitute a quorum. The meetings of the Council shall be held at the call of the chairman or whenever the majority of the members so request.

E. Members shall receive such compensation for the performance of their duties as provided in § 2.2-2813. All members shall be reimbursed for all reasonable and necessary expenses incurred in the performance of their duties as provided in §§ 2.2-2813 and 2.2-2825. Funding for the costs of compensation and expenses of the members shall be provided by the Department.

F. The Department shall provide staff support to the Council. All agencies of the Commonwealth shall provide assistance to the Council, upon request.

§ 32.1-73.22. Report.

The Commissioner shall report annually by December 1 to the Governor and the General Assembly on the Council's recommendations related to efforts to improve awareness of sickle cell disease and sickle cell trait. Such report shall be submitted for publication as a report document as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents and reports. The chairman shall submit to the Governor and the General Assembly an annual executive summary of the interim activity and work of the Council no later than the first day of each regular session of the General Assembly. The executive summary shall be submitted as a report document as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents and reports and shall be posted on the General Assembly's website.

2. That the initial appointments of members of the Advisory Council on Sickle Cell Disease shall be staggered as follows: one member who is an individual who has been diagnosed with sickle cell disease or sickle cell trait or is the family member of a person who has been diagnosed with sickle cell disease or sickle cell trait and one member who is a health care provider who specializes in hematology to be appointed for a term of two years; one member who is an individual who has been diagnosed with sickle cell disease or sickle cell trait or is the family member of a person who has been diagnosed with sickle cell disease or sickle cell trait and one member who is a representative of a community-based organization with experience addressing the needs of

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individuals with sickle cell disease for a term of three years; and one member who is an individual **58**

- who has been diagnosed with sickle cell disease or sickle cell trait or is the family member of a
- person who has been diagnosed with sickle cell disease or sickle cell trait, one member who is a **59**
- health care provider who specializes in hematology, and one member who is a representative of a community-based organization with experience addressing the needs of individuals with sickle cell **60**
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- disease for a term of four years. **62**